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Gridley, Kate orcid.org/0000-0003-1488-4516, Aspinall, Fiona Jane orcid.org/0000-0003-3170-7570, Parker, Gillian Mary orcid.org/0000-0002-2221-6748 et al. (4 more authors) (2018) *Supporting Carers of People with Dementia : A mixed methods evaluation and feasibility study (January 2018)*. Report. Social Policy Research Unit, University of York

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Supporting Carers of People with Dementia

A mixed methods evaluation and feasibility study (January 2018)

Unpaid carers are the mainstay of the UK care system for people with dementia. Yet caring can have an impact on the well-being and health of the carer.

Admiral Nursing is the only specialist nursing service in the UK that specifically focuses on supporting carers of people with dementia, but evidence of its effectiveness, costs, and relationships to other services is limited. This project aimed to address this gap and explore the feasibility of full-scale formal evaluation.

The aims of the research

Unpaid care can be provided by partners, family, friends or neighbours. Through this research we aimed to:

- 1) Understand more about who uses Admiral Nursing services, how the services operate and what we can learn about outcomes from the existing Dementia UK database
- 2) Hear, from the perspectives of unpaid carers themselves, what outcomes are influenced by the support they receive, and what happens when support is absent or of poor quality
- 3) Develop and test data-collection methods for future cost-effectiveness research incorporating the outcomes prioritised by carers
- 4) Explore the cost-effectiveness of Admiral Nursing, as against usual care, through a survey of carers in 34 areas of England
- 5) Explore the perceived system-wide impact of support for carers of people with dementia

Overview of findings

- ❖ From the existing data we saw that Admiral Nurses are successfully targeting the most complex cases and, on average, the needs of carers being supported by Admiral Nurses reduced over time. However, we did not have the right information to link this reduction to the activity of the Admiral Nurses.

Researchers

Kate Gridley, SPRU
Fiona Aspinall, SPRU
Gillian Parker, SPRU
Helen Weatherly, CHE
Rita Faria, CHE
Francesco Longo, CHE
Bernard Van Den Berg, CHE

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Project webpage

<http://bit.ly/2ktFW8e>



Overview of findings (continued)

- ❖ In interviews and focus groups with 35 carers of people with dementia we heard how the support they get can influence their health, quality of life and confidence in caring. Carers value continuity and 'feeling supported': having contact with a professional who understands dementia and has the time to get to know their situation could improve carers' confidence and help them to feel supported.
- ❖ In-depth interviews with 20 key professionals found that the wider impact of services like Admiral Nursing are not well understood.
- ❖ Our survey, completed by 346 current carers of people with dementia, showed the heavy burden that carers carry, the low levels of support that they get from health and social care services, and the financial impact of paying for services.
- ❖ Carers who used Admiral Nursing were older and more heavily involved in caring than other carers. Taking these differences into account, their quality of life appeared slightly better than that of carers without Admiral Nursing. However, this difference was not statistically significant, so the apparent benefit may have been due by chance.
- ❖ The costs of the health and social care services used by both groups were similar.

Stage 1: The Dementia UK database

Dementia UK supplied us with anonymous information about nearly 25,000 cases of a person (carer or person with dementia) receiving Admiral Nursing support. Three hundred and fifty-eight of these cases had information from needs assessments from at least three points in time. We used these 358 cases to examine change over time.

A third of carers receiving Admiral Nursing support were over 75 and caring for someone over 75 years of age, and the predominant relationship between carer and person with dementia was spouse or partner. Over a third of referrals came from mental health services and almost a fifth were self-referrals.

Forty per cent of person with dementia/carers pairs had been assessed as 'at risk' at some point in their contact with the service. Admiral Nurses worked with carers, the person with dementia and other agencies, including the police, to reduce the likelihood of harm from these risks. Positive change over time was evident in relation to several outcome areas, including medication management, insight into dementia, coping with the symptoms of dementia, informal support and time for the carer.





Stage 2: The outcomes affected by carer support

Focus groups and interviews with 35 carers of people with dementia (in Admiral Nursing and non-Admiral Nursing locations) identified three key outcomes influenced by carer support (and Admiral Nursing in particular):

1) Confidence in caring: which carers said they gained when they were supported by a specialist in dementia who knew them well. Having an ongoing relationship with such a professional, who they could turn to as things progressed, could give carers the confidence to continue caring in spite of the difficulties and uncertainty they faced. We measured carer confidence using the Caregiver Self-Efficacy for Managing Dementia scale.

(Ref: Fortinsky, R.H., Kercher, K. and Burant, C.J., 2002. Measurement and correlates of family caregiver self-efficacy for managing dementia. *Aging & Mental Health*, 6(2), pp.153-160.)

2) Care-related quality of life: we measured this using ASCOT Carer as this assesses several aspects of carers' lives that the carers we spoke to felt carer support could influence. For example, it was the only tool in our shortlist with a question on 'feeling supported and encouraged'.

(Ref: Rand, S.E., Malley, J.N., Netten, A.P. and Forder, J.E., 2015. Factor structure and construct validity of the adult social care outcomes toolkit for carers (ASCOT-carer). *Quality of Life Research*, 24(11), pp.2601-2614.)

3) Carer health (mental and physical): carers spoke about the impact of caring on their physical and mental health. Examples were given where stress and sleep deprivation had led to physical illness, such as shingles.

Stage 3: National survey of carers

We received 346 completed questionnaires from current carers of people with dementia; 46% from Admiral Nursing service users and 54% from carers in areas that did not have Admiral Nursing. As a group, these carers were older and more intensely involved in caring than all UK carers of people with dementia. Financial difficulties, lack of opportunities for a break and greater reported severity of dementia were associated with worse outcomes for carers in the survey.

Carers with Admiral Nursing were more likely than those in areas without Admiral Nursing to be:

- ↑ Older
- ↑ The main carer
- ↑ Caring for a spouse/partner
- ↑ Co-habiting with that person
- ↑ Experiencing financial difficulties
- ↑ Providing personal and physical care
- ↑ Caring for 18 hours or more a day

Controlling for differences between the Admiral Nursing and non-Admiral Nursing groups:

- ↑ Carers with Admiral Nursing appeared to have better outcomes (but this difference was not statistically significant).
- = There were few differences in costs to health and social care (attributable to carers' own service use or that of the people they cared for).



Stage 4: The wider impact of carer support

Across four English areas (two with and two without Admiral Nursing), we identified 58 professional stakeholders in key positions, 20 of whom agreed to be interviewed by telephone. It was clear from these interviews that the impact of carer support services on other services (including hospital and care home admissions, use of social services and general practice) is not well understood and was rarely measured. Interviewees suggested that such effects are particularly difficult to capture since prevented crises (for example, avoided admissions, or fewer referrals to social services) cannot be observed without a control group. Nevertheless, the consensus was that these preventative services were valuable and did reduce pressure on statutory services.

A common theme across all areas was the significant financial pressure that commissioners and providers were under. Admiral Nurses were valued, but seen as an expensive resource. Given the challenges of reaching, and providing continuity to the growing numbers of people with dementia and their carers, the tiered model established in some areas (where Admiral Nurses worked with and mentored less qualified support workers, escalating/de-escalating cases as and when necessary without discharging them) appears sensible. It remains to be seen whether the wider impact of such an approach can be demonstrated.

Conclusions, strengths and limitations

This research has thrown important new light onto specialist nursing support for the carers of people with dementia who are most heavily involved in caring and, in many cases, in later old age themselves. It suggests that such support may be a key element in enabling carers to continue their support to the end or very close to the end of the dementia journey.

The outcome measures we chose for the survey were seen by carers as appropriate when we tested them, and were completed well in the survey. They have already proved attractive to a range of dementia care service providers wishing to evaluate their own work. We conducted a one-off survey which means our conclusions about differences between outcomes for carers with and without Admiral Nursing are not definitive. However, given the underdeveloped state of knowledge about the costs and effectiveness of support for any type of carer, this research represents a substantial step forward.

For more information about this research contact: Kate Gridley kate.gridley@york.ac.uk
or go to the SPRU project webpage <http://bit.ly/2ktFW8e>